137

END-OF-LIFE CARE IN HEMATOLOGY AND STEM CELL TRANSPLANT PATIENTS AND EVALUATION OF A HEMATOLOGY-QUALITY OF DYING ASSESSMENT (H-QODA)

Rowlings, P.[1,2], Zhang, H.[1], Rohr, Y.[3] [1]Newcastle Mater Hospital & HAPS, Waratah, Newcastle, NSW, Australia; [2]HMRI & Newcastle University, Newcastle, NSW, Australia; [3]Division of Palliative Care, Newcastle Mater Hospital, Waratah, Newcastle, NSW, Australia.

Background: Improving quality of end-of-life (EOL) care becomes the highest priority when prolonging survival is no longer possible. To identify factors impacting EOL care, we retrospectively studied patients (pts) dying over 12 months managed by a single unit. We also evaluated a Hematology-Quality of Dying Assessment (H-QODA), modified from a QODA proposed for pts with end stage renal disease. **Methods:** Patients' deaths were identified from hospital lists, newspapers and referring doctors and family members. Data relating to care during EOL were extracted from medical records. To identify pts in whom attempts by the Hematology unit to improve EOL care would be most relevant, pts were considered as falling into two groups. Group (Gp) A consisted of pts dying while under active management of the haematology team (seen by the team within 3 mos of death and dying from their haematological malignancy) and Gp B, pts not seen within 3 months of death, or dying of an unrelated cause. As a pilot study to evaluate the H-QODA, a random sample of 16 pts from Gp A were studied more extensively. Five domains were analysed & scored: 1) pain during last week of life; 2) non pain symptoms during last week of life; 3) advance care planning , 4) peace and dignity in last week of life and; 5) time to death from the change of focus to EOL care. Each domain was scored 0-2, from worst to best, for a possible total score of 10 for a very high quality of dying assessment. **Results:** During the study period (1 Jul 04 to 30 Jun 05), 211 pts died as part of the management of approximately 3000 pts by the unit. Of the 211 pts who had died, 98 were in Gp A and 113 in Gp B. Thirteen pts died who had received HSCT, 2 from allogeneic donors and 11 autologous. In preliminary analyses, pts in Gp A were significantly younger (71.5 vs 75yrs) than Gp B ($p=0.04$), and had a greater proportion of aggressive diagnoses (acute leukaemia, multiple myeloma and NHL) ($p=0.001$). Twenty one percent of pts in Gp A died in the adjacent hospice facility, compared to 12% in GpB ($p=0.005$). In the random sample of pts from Gp A, the H-QODA ranged from 4 to 9 with an average of 6.5. Inter-rater reliability testing and correlation between pt, family, disease and management factors and the H-QODA are proceeding. **Conclusion:** An H-QODA was developed based on domains relevant at EOL. Such a tool, if validated, would be useful for assessing impact of multidisciplinary care programs aimed at improving EOL care.

138

HYPOTHYROIDISM IN LONG-TERM SURVIVORS AFTER TBI BASED ALLOGENEIC STEM CELL TRANSPLANTATIONS – IMPACT OF CHRONIC GRAFT VERSUS HOST DISEASE AND TBI DOSE

Savani, B.N.[1], Shenoy, A.[1], Kozanas, E.[1], Wisch, L.[1], Singh, A.K.[2], Childs, R.[1], Barrett, A.J.[1] [1]Hematology Branch, National Heart Lung and Blood Institute, NIH, Bethesda, MD; [2]Radiation Biology Branch, National Cancer Institute, NIH, Bethesda, MD.

Between 09/1993 and 04/2005, 189 patients received TBI-based allogeneic stem cell transplantation (SCT) for hematological malignancies from HLA- identical sibling. One hundred thirty four patients (with minimum 1 year follow-up) were studied for thyroid function at a median of 4.5 (range 1-13) years post SCT. Median age at transplant was 36 years (range 10-55). Seventy six (57%) received 13.6 Gy TBI with no lung shielding, 58 (43%) received 12 Gy with lung shielding (total lung dose 6Gy). Twenty-two (16.4%) were subclinical hypothyroid (by elevation of TSH level only) and 17 (12.6%) had overt hypothyroidism at a median of 2.4 (range 1.5-4.5 years) and 2.6 (range 1.5-5 years) after SCT respectively. In univariate analysis overt and subclinical hypothyroidism was significantly associated with age > median, TBI dose > 12 Gy, and presence of chronic GVHD: Fourteen of 75 patients with chronic GVHD vs. 3/59 ($p=0.02$) developed overt, and 17/75 vs. 5/59 ($p=0.03$) developed subclinical hypothyroidism. In multivariate analysis TBI dose >12 Gy and cGVHD were independently associated with increased risk of overt hypothyroidism: (TBI dose >12Gy RR 2.4, $p=0.04$; chronic GVHD RR 2.6, $p=0.03$). TBI dose and cGVHD were also risk factors for subclinical hypothyroidism (RR 3.8, $p=0.02$ and RR 3.8 $p=0.02$ respectively). Fifteen patients (8 normal and 7 abnormal thyroid functions) were studied for anti-thyroglobulin and anti-peroxidase antibodies, 7 patients were tested positive. There was no association of occurrence of thyroid antibodies with hypothyroidism (5/7 vs. 2 /8) nor with cGVHD. In conclusion thyroid dysfunction is relatively common after SCT and is more likely to occur in older patients receiving higher TBI doses developing cGVHD. Thyroid dysfunction did not appear to be related to a classical autoimmune process.

139

A JOURNEY TO PERFORMANCE EXCELLENCE UTILIZING THE MALCOLM BALDRIGE MODEL IN A BONE MARROW TRANSPLANT UNIT

Schriber, J.P.[1,2], Majkowski, G.O.[1], Kendrick, S.[1], Simpson, E.[1], Sarkodee-Adoo, C.[1,2], Briggs, A.D.[1,2], Forman, S.J.[1,2], Alvarnas, J.C.[1,2] [1]City of Hope Banner BMT Unit, Phoenix, AZ; [2]City of Hope, Duarte, CA.

Continuous quality improvement is critical for organizations as they strive to provide performance excellence. The Baldrige award used to recognize role model behaviors is the highest achievement in the United States for business and service excellence. Health care currently comprises over half of all applicants. The approach is unique in that it is not prescriptive, rather it provides a framework for the description of what the applicant does, how they perform this service and how well they compare to others providing similar services. Although few win, applying forces the applicant to examine how they perform core services using 6 broad categories: Leadership, Strategic Planning, Customer Service, Information management, Human Resource Focus and Process management. For each a results section evaluates how well you perform relative to your competition. Such an approach is well suited to transplant centers. To prepare our application we divided into groups focusing on each core area to prepare answers to the criteria questions addressing issues such as ethics, employee and client satisfaction. These were reviewed by senior leadership to create the final document. As we prepared opportunities for improvement (OFIs) were identified, new processes and corresponding measurement tools were developed. Even before submission this allowed our program to refine and align strategic goals and integrate these throughout the entire BMT team. It also significantly enhanced team building by providing an atmosphere of ownership. For some organizations self assessment may be sufficient. Programs who formally apply are evaluated by specially trained examiners who provide feedback on strengths and OFIs based on the criterion outlined in the application. Programs who move forward to consensus or site visit receive feedback at the highest level achieved. Importantly the feedback does not suggest how to improve but rather highlights areas that may not have been addressed and why they are important to achieving your goals. The program determines how best to address these gaps. As a result of our feedback some changes we implemented included modifying the leadership structure, developing a formal strategic plan, new surveys to capture referring physician satisfaction and preferences. Using the Baldrige model aligns leaders, provides focus to organizational priorities and gives an outside perspective measured against other similar high performing organizations.

140

A SURVEY OF HEMATOPOIETIC CELL TRANSPLANT SURVIVORS AND SPOUSES: WHAT ARE THE MAJOR ISSUES OF CONCERN POST-TRANSPLANT?

Stewart, S.K.[1] [1]Blood & Marrow Transplant Information Network, Highland Park, IL.

Between July 19 and October 1 2006, BMT InfoNet conducted an online survey to identify issues of concern to HSCT survivors and their families. Five hundred and thirty eight people completed the survey including 369 survivors, 63 survivor spouses, and 74 parents.